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## Whose mammogram is this anyway? Perspectives on technology, breast health and mammography

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### ABSTRACT

There is an increasing demand to ensure that emerging health technologies are patient-centred. Yet, understanding what constitutes patient-centredness can be a complex task, particularly in relation to screening technologies, where lack of patient-centred design can result in decreased compliance with screening recommendations. This holds true for breast cancer screening, where nearly 80% of women do not comply with screening mammography recommendations. To support patient-centred design of breast screening systems, semi-structured interviews were conducted with participants who could provide diverse perspectives on breast screening, including mammographers, breast cancer survivors, and self-identified mammography avoiders. Interviews explored opinions and attitudes surrounding current screening technology and systems, and ways in which screening might be conducted in the future. Using an inductive, constructivist approach, we identified several themes that should be considered when designing breast screening technology and systems. Concerns regarding the current processes and needs for support in relation to self-advocacy were revealed. Interest in improved technology was wide-spread, but feelings of inadequacy limited acceptance of self-screening designs. This study showcased the opportunities for design scholarship to improve the breast cancer screening process and, potentially enhance the patient-provider relationship.

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Breast cancer; care anywhere design; patient empowerment; screening guidelines

## Introduction

The American health care reform law, the Patient Protection and Affordable Care Act (2010) placed an emphasis on demonstrating that the care provided to patients is safe and effective, and that patients and their families are engaged in the health care process (Blumenthal 2010). These reforms led to the prioritization of research on patient-centred outcomes, including the assessment of prevention, diagnosis, and treatment options and the reduction of health

disparities (Selby, Beal, and Frank 2012). This new focus on patient-centredness at the national level came at a time of uncertainty and upheaval regarding breast cancer screening, shedding light on new opportunities for innovation in the design and development of care protocol and technology. Studies questioning the risk vs. benefit of screening mammography, particularly for individuals between the ages of 40 and 50 (U.S. Preventive Services Task Force 2009), have raised confusion surrounding the safety and effectiveness of breast cancer screening and concerns about how to incorporate the patient's perspective into the screening process (Pace and Keating 2014). Early detection and treatment of breast cancer as facilitated by routine mammographic screening substantially reduces the risk of death from cancer (Paap et al. 2014). Yet, only 21% of women comply with current mammography screening guidelines (Meadows et al. 2011). The emphasis on patient-centred research, as it relates to breast cancer screening, has primarily focused on correlational studies that relate demographic factors to the level of initial and follow-up screening compliance (e.g. Viens et al. 2017; Seven et al. 2017; McDonald, Wang, and Liu 2017; Goldzahl 2017) and developing educational interventions to improve patient compliance with current screening systems and their existing imaging technologies (e.g. Knerr et al. 2017; Knerr et al. 2017; Borrayo, Rosales, and Gonzalez 2017; Lee et al. 2017). While new technologies are being developed to augment the existing breast screening systems and technologies (e.g. Walter, Knight, and Lilge 2017; Mokale et al. 2017; Kranold, Hazarika, and Popović 2017), the development of these technologies are focused on the fabrication of prototypes with diagnostic promise. There currently exists a great opportunity to leverage understanding of women's perceptions of technology, breast health, and mammography, to inform both systems and technology design.

The relationship between morality and health raises questions around notions of risk and self-advocacy in an environment of rapidly changing and contested breast screening recommendations. In technologically advanced societies, managing health risks is assumed to be part of the moral obligation to seek health (Crawford 2006). Sociocultural aspects influence health-related decisions throughout the life course, and the relationship between social networks, health and well-being in general have been long established (Cattell 2001; Smith and Christakis 2008), as have social networks and breast health. Health-seeking behaviour is generally thought to be responsible and rational, to reduce risk of serious illness, and to reflect current 'expert recommendations' (Vahabi and Gastaldo 2003, 245). These assumptions fall in line with current scholarship on achieving and maintaining the status of 'healthy person' as a moral obligation (Clarke and Bennett 2013; Crawford 2006). How does this intertwining of social and moral obligation play out in terms of screening compliance?

Research addressing the factors impacting screening compliance include social dynamics influencing the likelihood of women being screened (Allen et al. 1999), health beliefs associated with screening adherence and compliance (Aiken et al.

1994), strategies for increasing adherence and compliance with screening guidelines (Andersen et al. 2003, 318–319; Denberg, Wong, and Beattie 2005), and insight regarding risk assessment and the rejection of screening guidelines by some women (Vahabi and Gastaldo 2003). Patient perceptions of health-related screenings can function as barriers to mammography screening. For example, concerns about screening efficacy (false positives/negatives); concerns about the mammography procedure itself (pain, side effects, radiation); fear of cancer diagnosis making insurance rates increase; and practical concerns such as screening costs, location, transportation, and availability of child care have all previously been identified as barriers to mammography (Watson-Johnson et al. 2011).

### *Mammography screening guidelines in the United States*

The US Preventive Services Task Force (USPSTF), established in 1984, is a government-supported panel of national experts in evidence-based medicine (About the USPSTF - US Preventive Services Task Force, n.d.). Evidence-based medicine is the process of implementing health care interventions which have been validated through scientific investigation. The USPSTF rates a wide variety of screening and prevention recommendations as A, B, C, D or I based on the quality of the research evidence supporting the recommendation and the risks the screening or prevention recommendation poses to the individual. These grades indicate the evidence supporting the net benefit of undergoing a screening procedure. The USPSTF recommends that providers routinely offer procedures graded as A or B to their patients because there is a high certainty that the net benefit to the patient is moderate to substantial (U.S. Preventive Services Task Force 2009). Procedures rated with a C have a moderate certainty of a small net benefit and, from 2007 to 2012, the USPSTF recommended that providers offer those services ‘only if other considerations support the offering or providing the service in an individual patient’ (U.S. Preventive Services Task Force 2009, 724). Procedures rated with a D are discouraged because the USPSTF has determined that there is a ‘moderate to high certainty that it provides no net benefit or that the harms outweigh the benefits’ (AHRQ 2014). The USPSTF also issues ‘I’ ratings when evidence is lacking, conflicting or the balance of harms versus benefits cannot be determined. In November 2009, the USPSTF first issued a C rating for screening mammography in women aged 40–49 (U.S. Preventive Services Task Force 2009). At that time, the USPSTF issued the recommendation to discontinue routine screening of women between ages 40 and 49. This recommendation was based on ‘psychological harms, unnecessary imaging tests and biopsies in women without cancer, and inconvenience due to false-positive screening results’, with false-positives comprising the primary risk for women aged 40–49 (U.S. Preventive Services Task Force 2009, 717). Because the incidence of breast cancer is lower during ages 40–49, the relative benefit is not as great as it is for women aged 50–74. A rating of B was issued regarding screening

mammography for women aged 50–74, with recommendations to reduce screening frequency to every two years, from the previously recommended annual frequency. The Task Force felt that biennial screening preserved the majority of the benefits of screening while cutting the harms in half. They issued a D rating with regard to clinicians teaching breast self-examination to their patients, determining that the two available studies demonstrated increased imaging and biopsies for women performing breast self-examination, causing the harms to outweigh the benefits as assessed by the USPSTF. Finally, the USPSTF issued an I rating for mammography screening for women over the age of 75, for clinician performed breast examinations, and for the use of digital mammography or MRI screening modalities as a substitute for film-based mammography, because research evidence does not currently demonstrate a benefit of those screening protocols. The Patient Protection and Affordable Care Act 'requires Medicare and all qualified commercial health plans to cover routine preventive services grade A and B by the USPSTF' (Centers for Disease Control and Prevention 2011). The C rating for screening mammography between the ages of 40 and 49 effectively eliminates insurance and Medicare coverage for a screening protocol that has been considered standard for decades.

The USPSTF recommendations starkly contrast with the recommendations of the American College of Radiology (ACR), the organization which informs the practice of mammography technologists and serves as the accreditation body for mammography facilities (Mainiero et al. 2013). The ACR Appropriateness Criteria are evidence-based guidelines that recommend annual screening mammograms for asymptomatic women starting at age 40, and annual screening mammograms starting at age 25 for carriers of the breast cancer 1 gene and untested relatives of carriers, and women with first-degree relatives with premenopausal breast cancer. They further recommend supplementing mammography with MRI or ultrasound of the breast for women in high-risk populations (Mainiero et al. 2013).

The USPTF recommendations also diverge significantly from the recommendations of the American Cancer Society (ACS). The ACS first issued recommendations regarding breast cancer screening starting in 1976, recommending that annual mammography screening exams begin at age 40 (Chronological History of ACS Recommendations for the Early Detection of Cancer in People Without Cancer Symptoms, n.d.). In October 2015, the American Cancer Society surprised many in the mammography community by issuing a revision of their recommendations. They now recommend that screening mammography begin at age 45 and continue annually through age 54, with biannual screening recommended starting at age 55 (Grady 2015; Oeffinger et al. 2015). While these changes bring ACS recommendations closer to those of the USPSTF, significant incongruities remain between the two sets of guidelines. Both the American Cancer Society and the Mayo Clinic have issued statements in opposition of the USPSTF's recommendations (Mammogram Guidelines @ The Breast Cancer Site, n.d.). The

way in which USPTF guidelines are directly linked to Patient Protection and Affordable Care Act, without consideration of other evidence-based recommendations, has raised concerns about potential reduction or elimination of insurance coverage for breast screening outside the USPSTF guidelines (FORCE Response to USPSTF Guidelines on BRCA Testing, [n.d.](#)), effectively silencing many women's voices in their own screening choices.

### *eHealth, care anywhere and self-screening*

Calls for more personalized care and fewer one-size-fits-all approaches to screening guidelines have been echoed by the demands for smart devices to place more health-related information into the hands of the consumer. Recent advances in electronic health (eHealth) and telemedicine have introduced mobile devices into health-related self-management tools of people worldwide, creating opportunities for the highly personalized management of health conditions beyond the 'brick-and-mortar' care facility and extending access to new populations (Akters and Ray 2010; Silva et al. 2013). The rise in these more personalized and wireless technologies requires sustained interdisciplinary collaboration and transcendence of boundaries between design and engineering scholarship (Andre and Teller 2005, 90). Our project proposed to explore patient and health care provider perspectives on current breast screening practices and gauge the inclusion of greater patient engagement and control over the breast screening process, including opinions and attitudes about the use of hypothetical 'ideal' self-screening technology.

## **Methods**

### *Setting and sample*

Our study used qualitative interviews to explore the experiences, thoughts and opinions on the current state of breast cancer screening in the United States. Data collection took place between October 2014 and May 2015 in the Midwestern United States. This study was approved by the first and second author's University Institutional Review Board (IRB) prior to data collection and followed an IRB-approved technique of implied consent. All participants received an information sheet with study details, phone numbers and emails to address any concerns about their participation. They were given an opportunity to ask questions and verify that they were consenting to participate. At that point, participants were told that anyone not wishing to participate was free to leave the interview room. The remaining participants were informed that by staying for the interview, they were granting consent. Participants were paid a \$25 incentive for their time. Mammographic technologists also received continuing education credit for their participation.

We interviewed 31 participants from three different populations (groups interviewed separately): women aged 40–49 who have never been diagnosed with breast cancer but for whom screening mammography is recommended; breast cancer survivors of any age; and mammographic technologists of any age. This relatively small sample size allowed for more in-depth discussion about highly personal and sensitive issues. We used semi-structured questions in focus group interviews and three individual interviews (with survivors who could not attend the focus group but wanted to participate) to explore issues surrounding breast cancer screening. We included interviews with members of the health care workforce (technologists), to compare the personal perceptions of individuals as patients with those of the health professionals who perform breast cancer screening. Interview sessions were between 60 and 90 minutes each.

### **Recruitment**

Participants were recruited through the posting of ads in an electronic campus newsletter, academic medical centre newsletter and an advert in the state Radiologic Association Conference website, with a link to a Qualtrics<sup>®</sup> (2015) survey to screen for inclusion criteria. Potential recruits were prompted to submit their contact information if they were interested in learning more about the study. Those who did so were contacted via phone or email and invited to enrol in the study. One hundred and twenty-three participants responded to the advert and completed recruitment survey, 117 women fitted the project criteria, and 81 were willing to participate in-person interview. A total of 31 participants were interviewed.

### **Interview guide**

Individual and focus group interviews were used to explore the barriers and facilitators surrounding the screening process, attitudes and concerns of women based on their personal experiences with mammography, and issues regarding existing screening protocols, referral guidelines, modesty, privacy, pain, false positives, cancer recurrence, and dense breast tissue. The semi-structured interview approach allowed the participants to highlight the factors that were of greatest significance to them. In addition to their prior experiences, participants were asked to envision an ideal screening system. By keeping details of the system vague, the features discussed were the ones that were most meaningful to the participants. The focus group approach was selected to allow the participants to interact with, prompt and challenge one another. Specific questions included: Where do you get information about mammography and breast health? Tell me about your experiences with mammography; How do you feel about annual or semi-annual mammograms? What kinds of questions and concerns regarding mammography do you hear from other women? Do you know anyone who has cultural/religious-based concerns about being screened? If you

could create the ideal screening system for breast cancer, what attributes would you include?

### Analysis

All interviews were transcribed verbatim. Transcripts were coded by the first and second authors, using an iterative process. We used an inductive, constructivist grounded theory approach (Charmaz 2006) to create categories based on themes emerging from the transcripts. This approach was essential for capturing the issues that emerged from our qualitative individual and focus group interviews, as is the benefit of an inductive technique. Emerging concepts were documented in a summary table by the first author and second authors, and identified by codes. Coded concepts were grouped into themes, as they were compared among the members of our interdisciplinary team of investigators, refined and modified as necessary until overlapping or redundant codes were eliminated and consensus was reached between the first and second authors. Themes were checked against the transcripts and challenged by the third author, resulting in further refinement of the themes and consensus among all authors. The resulting themes and their definitions became our results.

### Results

We interviewed a total of 31 participants (appropriate size for a qualitative study), including 12 mammography technologists, 9 breast cancer survivors, and 10 women in the target age range (40–49) who had not been diagnosed with breast cancer. Among the 10 ‘never-diagnosed’ participants, 9 of them reported some degree of apprehension toward mammography and either refused to have a mammogram, or were previously adherent with regular screening, but have since stopped. The remaining participant in that group reported elevated hereditary risks for breast cancer, but had at the time of data collection not been diagnosed, and was adherent to screening recommendations by her physician. The participants across all groups ranged in age from 24–70, with the majority falling into the 40–60 age bracket. Most of the participants identified their ethnicity as white/Caucasian. The themes that emerged from our participant interviews included the need for patient-centredness to address uncertainty and frustration surrounding screening mammography, the pros, cons, and design requirements of the ‘care anywhere’ self-screening concept, and issues of trust and mammogram safety.

#### *Patient-centred care and empowerment: whose mammogram is this anyway?*

We asked participants in all three groups to discuss their feelings on mammography, and how the current breast cancer screening experience could be improved. Participants across all three groups expressed a desire for increased patient-centredness in care delivery. Patients and technicians shared

dissatisfaction over the ways in which mammograms are authorized by the health care and insurance systems. Participants shared their confusion over the appropriate age for receiving a mammogram, and expressed frustration over accessing the requirements for insurance coverage, the requirements for a physician referral, and the available appeal mechanisms in instances when a physician denies a patient request for a mammogram referral. Mammographic technologists reported their experiences with physicians who ordered inappropriate or 'wrong' tests for patients, for example, a screening rather than a diagnostic test when the patient has a suspected lump; or failed to acknowledge patient preferences, for example, ordering tests for patients who adamantly did not want them in some instances and discouraging patients who did want mammograms from requesting them in other instances. The following encounter between a technologist and an elderly patient illustrates this frustration:

I had a 103 year old lady come in for a mammogram from the nursing home that had to be transported in. She didn't want to be there, she's fighting and clawing. I'm like, you know, why? Why did this doctor order this, why?

One woman in her 40s (in the 'never-diagnosed' group) was surprised when her doctor did not refer her for a mammogram after she disclosed her family history of breast cancer. She assumed that disclosing a family history of breast cancer would result in a mammogram referral and perhaps the taking of a detailed health history. When her physician downplayed her concern, it caused her to question her own perception of risk, and whether a family history of breast cancer is truly significant in assessing risk.

When I was approaching 40, you know, oh, gosh, they're really going to want to follow me, you know, in my mind I had built it up into something I thought people would be more concerned about and I feel a very strong, I don't want to say 'lack of concern.' I don't know that it's a lack of concern, but ... not what I had anticipated. It's more, 'Oh, yeah. There are these new guidelines and you only have to do it [mammogram] every so often' and if I personally had a strong feeling about it, I guess I would be a little more insistent.

Questions regarding the appropriate circumstances under which mammograms should be performed reoccurred in these data. In the following instance, a new mother under the age of 30 shared her disappointment and frustration over having her concerns dismissed after she found a painful lump. She was ultimately diagnosed with breast cancer:

So she [physician] says to me that it's cysts, I have lumpy breasts; [avoid] salt and caffeine. And I said, 'No. This is not okay. I want to make sure that everything is all right because I've thought about it for a really long time, it's concerning to me. And I notice it even when I walk it's painful.' She said, 'Okay, I tell you what: I want you to reduce your salt and caffeine intake. Call me in a month.' And I thought, you have got to be kidding me. It's a mammogram ... I'm not asking you to hospitalize me and do some type of brain surgery. Give me a mammogram, that's it. It's like pulling teeth to have an X-ray or something.

### *Self-screening and care delivery: is new technology the answer?*

Overall, participants agreed that a convenient, affordable, pain-free and safe detection process would benefit women. When asked for details about what this ideal screening system or device would include, we found that participants were of two minds: (1) either they were reluctant to trust a screening device for home use, and wanted care to be 'left up to the experts', or (2) they expressed interest in breast cancer detection devices designed for self-screening, and believed it could be empowering for women. The mammographic technicians expressed their collective belief that continuous improvements in the design of breast health technology used by professionals will yield the ideal device. Survivors were equally divided among the two groups, with equal numbers in favour of and opposed to a self-screening device. The never-diagnosed participants were equally divided into three ways: in favour, against and in favour, but highly sceptical of a self-screening device.

### *Screening belongs in the professional domain*

Participants who were sceptical about the use of self-scanning devices (regardless of design) reported feeling that these devices were unnecessary because high-risk patients can have MRI in addition to mammogram screenings; a self-screening device would 'never work', would be too difficult for non-health professionals to learn how to operate, and could not be counted on to work properly or produce a high-quality image. If an image were to be produced, participants indicated that they would not want to see the image due to concern about bearing the responsibility for interpreting or reporting the image for follow-up care. Some of the breast cancer survivors were concerned about the additional burden placed upon patients, creating 'one more thing' they have to do. This additional burden was interpreted as counteracting the peace of mind that the device was supposed to provide, as in the following example from a survivor: 'I would be constantly worried about, you know, when I should do it, if I should do it, how often I should do it. I don't know. I think it would just add to my stress'.

Participants also called attention to the limitations of the design of technology, and the way disorganized care delivery can negate the benefits of even the finest, expertly designed equipment. These limitations were exemplified by the following account of the participant quoted above who went in for a routine mammogram, but through administrative or clerical error, the practice failed to contact her for a follow-up visit after cancer was detected:

So I went in for my mammogram, same place that I've been going forever, and the mammographers came in after I had had the mammogram and she said, 'Did you not come back last year?' And I said, 'No.' She said, 'No one contacted you to come back?' And I said, 'No.' So she said, 'Well, they should have.'

In the above case, a routine mammogram was sufficient for detecting breast cancer; however, human administrative error delayed the diagnosis for over one year. In this case, an improvement in the design of the care delivery system and protocol, rather than detection device, would have benefited the patient.

### *Self-screening would give peace of mind*

Participants who expressed support for and interest in a self-screening device for breast cancer detection shared their concerns about the safety of mammography, lack of confidence in self-examination by touch, and distrust in the 'gate-keeping' often found within the American medical system and health insurance system. They interpreted the use of a (hypothetical) high-quality self-screening device as empowering, offering a way to navigate their concerns. In the following excerpt, the cancer survivor, who had initial requests for screening denied, shared her enthusiasm for a self-screening device:

I want like a little hand sonogram thing. Why not? Just, I mean practitioners have to check gazillions of emails, so cache it in a file, look at it a year from now when you have time. You know, not really a year, but you know, or have someone screen the shots and say, 'No problem, no problem, no problem, no problem,' for all these patients. 'Oooh, might want to [come in for a mammogram].'

It would be incorrect to assume that negative clinical encounters are the sole driver behind the demand for self-screening tools. For example, in both of the above cases, participants experienced less than ideal clinical encounters; one woman's follow-up orders were overlooked and the other woman had to repeatedly demand a screening. Yet, these women have opposite opinions about the value of self-screening devices for safeguarding health, suggesting something more complicated at the root of contemporary health-seeking behaviour.

While an ideal self-screening device (if it were available) could potentially offer a sense of control over one's own health, and holds the promise of providing women access to information about their bodies without first obtaining permission from providers or insurance companies, several participants see a more limited, adjunctive role for such technology. For example, participants who approved of self-screening devices used in combination with mammography expressed that the combination of approaches would give them peace of mind and serve as an additional form of self-exam. One participant from the 'never-diagnosed' group believed the combination of self-screening and mammography under certain circumstances would play an important part in reducing 'paranoia' about having undetected cancer, especially given that she lost multiple friends to breast cancer. This combination approach also appealed to participants with a family history of breast cancer, cancer survivors who opted for a lumpectomy and were afraid of recurrence, and women who lacked confidence in self-exam by touch, as stated by this 47-year-old breast cancer survivor who works in health care: 'I think I would [use a self-screening device], because I'm

not real good about doing self-breast exams [by touch]... and so to have something that I knew was relatively reliable would be a benefit to me’.

### ***Avoiders: distrust of radiation and breast compression***

The never-diagnosed participants were the most likely to self-identify as distrustful of mammograms. Some of the women in this group expressed a general dislike of visiting a doctor’s office for routine or wellness care, due to reported dislike of having to disrobe, or being touched by strangers. One participant did not believe that her lifestyle was compatible with seeking routine wellness care or mammograms, and described her way of life as ‘living in the woods’, and ‘off the grid’. However, other mammogram ‘avoiders’ had much more specific concerns and expressed no aversion to health care in general. For example, several of our participants were interested in a self-detection device as an alternative, rather than an adjunct to mammography, due to concerns about ionizing radiation, and/or breast compression being harmful. These women shared that an ideal system would have no side effects, no radiation and would not cause pain. One of our participants was harmed by exposure to radiation in a non-medical context early in her life, complicating her health-seeking behaviour. She disclosed a desire to be screened for breast cancer, and had a history of breast cancer in her family, but was afraid that no safe alternative existed for someone with her background:

I have family history. My mom died 70 from breast cancer and then my physician asked me last year at 40 to start to do mammograms. I refused, because I’m from Ukraine. I grew up next to Chernobyl. I got a lot of radiation. I’m suffering from tumours all my life and ... have a lot of surgeries, so my physician, and another doctor ... they decided to [delay mammography] start to do mammograms ... to me at 55.

Other participants expressed distrust of mammography itself, and fear that it causes or spreads cancer. One participant shared that she delayed having an initial mammogram due to anxiety over mammography being somehow related to causing cancer. Her fears were validated by friends expressing similar concerns:

I didn’t do mine till I was 43, ‘cause I was I’m convinced the thing causes breast cancer. I just know that a lot of people have breast cancer now more than ever and I don’t know. I just think it’s a theory that ... you know, why is it now more than ever than before? Because more people are being examined, I’m sure, but I don’t know. I just think it might be related, causing it.

She elaborated further:

I thought I was kind of crazy until one of my friends, she had the same theory and I was like, ‘Oh, okay, then yeah. She has not, she’s 48 and she has not been to the, she has not had an exam yet, ‘cause she refuses.

Comments like these connected to a larger sense of mistrust – both that doctors are ordering mammograms that women don’t really need, or that the

equipment itself is harmful to their health. With the exception of the woman who grew up in the Chernobyl aftermath, participants who expressed these concerns did not indicate whether they had ever discussed them with a physician, but did indicate that members of their social networks influence screening behaviour.

## Discussion and conclusion

These individual and focus group interviews illuminated a variety of concerns and frustrations about breast cancer screening and breast health, particularly regarding inconsistencies between current physician and mammography technologist screening guidelines, the lack of patient centredness in the system design of care delivery, and exposed conflicting views of health-seeking behaviour with regard to beliefs about the safety and appropriateness of self-screening. The risk discourse documented here serves to highlight discrepancies between health care policies and the actual implementation of care governed by such policies. The design fields are in a unique position to help fill the aforementioned gap between patients, providers and policy-makers. Interestingly, the participants who sought as well as the participants who avoided mammography were both doing so for the sake of health. While seemingly counter-intuitive, these participant responses were manifestations of the culturally ingrained responsibility to assess risks and mitigate them to achieve and maintain wellness discussed by Crawford (2006).

Guidance to mammographers regarding the frequency and appropriate age range for screenings is different than the guidance to physicians, so it is not surprising that patients are receiving conflicting information. Conflicting information fuelled a desire for devices designed for self-screening among some of our participants. The mammographers in our study firmly believed in annual screening for women starting at age 40, yet their patients were being referred (at the time of data collection) for screenings every other year. In the wake of controversy surrounding national guidelines for breast cancer screening, both the survivors and mammogram avoiders in our study reported a sense of uncertainty when it came to the recommended age for receiving a mammogram. Participants wanted accurate information provided in language they could understand, and they wanted to feel that their concerns were heard and respected. Participants across all groups rejected one-size-fits-all screening guidelines, expressing support for a more customized approach to breast cancer screenings. These findings support recommendations that physicians need to be more aware of how they communicate the risks and benefits of mammography, and current literature on the 'individualization of screening decisions' (Pace and Keating 2014, 1330).

Our results were consistent with the literature on psychosocial issues and mammography avoidance (Watson-Johnson et al. 2011), for example, patient

embarrassment about exposing body parts to strangers, lack of breast cancer in family history, a family history of breast cancer generating fear about receiving 'bad news', or assigning one's own health a lower priority relative to family obligations were all listed as reasons for avoiding mammograms in this study. Andersen et al. (2003) noted that generating fear and worry about cancer can be counterproductive, and negatively impact a woman's quality of life, and 'May prevent very worried women from getting mammograms' (381). All of these concerns, if taken into account, are valuable in their potential to inform design scholarship.

Our study brought to light opposing opinions about screening technology that could be used by women in their own homes. The possibility of a self-screening device was met with suspicion by some of our participants and embraced by others, revealing a type of risk discourse around the notion of actively participating in the screening of one's own body. Those that held more sceptical views about self-screening expressed a belief that care belongs in hands of experts, and were concerned about the quality of devices designed for home-use, as well as the burden self-screening (by device) could potentially place on the patient. Participants also called attention to the limitations of the design of technology, and the way disorganized care delivery can negate the benefits of even the finest equipment, as in the example of the woman who had her referral for follow-up care lost due to administrative error. Participants were less aware of the significance of the design of care delivery systems.

Participants who embraced the idea of devices designed for self-screening indicated that they found them [potentially] empowering, and stressed the importance of self-advocacy. These participants interpreted self-screening devices as tools for helping them safeguard their health, either as adjunct or alternatives to mammography. In some cases, their risk discourse included the opinions of friends and family regarding whether or not to seek out or avoid a mammogram. The full extent to which social networks play a role in cancer screening-related decision-making will require further exploration.

Participants were asked to describe an ideal (but hypothetical) breast cancer screening device and also asked if they would consider a device intended for home use. From these discussions, the contrasting responses mentioned above were collected. These contrasting narratives provide insight into the motivations behind complex health-related behaviour, which is potentially helpful for the design fields (for example, desire for radiation-free device, more choices in screening technology beyond traditional mammogram, self-screen device for care anywhere, outside brick-and-mortar facilities).

These findings suggest that the design of new screening technologies has the potential to strengthen the patient-provider relationship with regard to breast health decision-making, particularly as patients work to make sense of shifting guidelines and contested screening recommendations. More research is necessary for comprehending the role social networks play in breast health decision-making,

and the potential of the design fields, to create systems as well as devices that shift the locus of control toward patients. Models such as the Technology Acceptance Model (TAM) or a revised version of it, could offer insight into motivation of end-users and prediction of populations that are more or less likely to adopt these technologies (Davis 1985).

## Limitations

While appropriate for a qualitative study, the small number of participants and limited geographical span (Midwestern US) of this study limit its generalizability; however, we believe these results offer transferability for mammography technologists, cancer survivors and women who are mammography-reluctant in multiple contexts.

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## Notes on contributors

**Allison Kabel** is a medical anthropologist at the University of Missouri who has conducted research in health-related settings in the United States, the United Kingdom and Canada. Her research interests include the concept of personhood, social participation and issues at the intersection of culture, health and identity.

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## References

"About the USPSTF - US Preventive Services Task Force." n.d. Retrieved October 19, 2015, from <http://www.uspreventiveservicestaskforce.org/Page/Name/about-the-uspstf>

- Aiken, Leona S., Stephen G. West, Claudia K. Woodward, and Raymond R. Reno. 1994. "Health Beliefs and Compliance with Mammography-Screening Recommendations in Asymptomatic Women." *Health Psychology* 13 (2): 122–29. doi:10.1037/0278-6133.13.2.122.
- Akter, S., and P. Ray. 2010. "mHealth - An Ultimate Platform to Serve the Unserved." *Yearbook of Medical Informatics* 94–100.
- Allen, J. D., G. Sorensen, A. M. Stoddard, K. E. Peterson, and G. Colditz. 1999. "The Relationship between Social Network Characteristics and Breast Cancer Screening Practices Among Employed Women." *Annals of Behavioural Medicine* 21 (3): 193–200.
- Andersen, M. R., R. Smith, H. Meischke, D. Bowen, and N. Urban. 2003. "Breast Cancer Worry and Mammography Use by Women With and Without a Family History in a Population-Based Sample." *Cancer Epidemiology Biomarkers & Prevention* 12 (4): 314–320. <http://cebp.aacrjournals.org/content/12/4/314>
- Andre, D., and A. Teller. 2005. "Health Care Anywhere, Today." *Studies in Health Technology and Informatics* 118: 89–110.
- AHRQ. 2014. *Appendix A: How the U.S. Preventive Services Task Force Grades Its Recommendations*. Rockville, MD: Agency for Healthcare Research and Quality. <http://www.ahrq.gov/professionals/clinicians-providers/guidelines-recommendations/guide/appendix-a.html>
- Blumenthal, D. 2010. "Launching HITECH." *New England Journal of Medicine* 362 (5): 382–385.
- Borrayo, Evelinn A., Monica Rosales, and Patricia Gonzalez. 2017. "Entertainment-Education Narrative Versus Nonnarrative Interventions to Educate and Motivate Latinas to Engage in Mammography Screening." *Health Education & Behavior* 44 (3): 394–402.
- Cattell, V. 2001. "Poor People, Poor Places, and Poor Health: The Mediating Role of Social Networks and Social Capital." *Social Science & Medicine* 52 (10): 1501–1516. doi:10.1016/S0277-9536(00)00259-8.
- Centers for Disease Control and Prevention. 2011. "Health Plan Implementation of U.S. Preventive Services Task Force A and B Recommendations—Colorado, 2010." *MMWR. Morbidity and Mortality Weekly Report* 60 (39): 1348–1350.
- Charmaz, Kathy. 2006. *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Pine Forge Press.
- "Chronological History of ACS Recommendations for the Early Detection of Cancer in People Without Cancer Symptoms." n.d. Accessed 19 October 2015. <http://www.cancer.org/healthy/findcancerearly/cancerscreeningguidelines/chronological-history-of-ac-recommendations>
- Clarke, Laura Hurd, and Erica V. Bennett. 2013. "Constructing the Moral Body: Self-Care Among Older Adults with Multiple Chronic Conditions." *Health* 17 (3): 211–228. doi:10.1177/1363459312451181.
- Crawford, Robert. 2006. "Health as a Meaningful Social Practice." *Health* 10 (4): 401–420. doi:10.1177/1363459306067310.
- Davis, Fred D. 1985. "A Technology Acceptance Model for Empirically Testing New End-User Information Systems: Theory and Results." PhD diss., Massachusetts Institute of Technology.
- Denberg, T. D., S. Wong, and A. Beattie. 2005. "Women's Misconceptions About Cancer Screening: Implications for Informed Decision-Making." *Patient Education and Counseling* 57 (3): 280–285. doi:10.1016/j.pec.2004.07.015.
- "FORCE Response to USPSTF Guidelines on BRCA Testing." n.d. Accessed 19 October 2015. <http://www.facingourrisk.org/our-role-and-impact/advocacy/current-actions/USPSTF-draft-guidelines-hboc.php>
- Goldzahl, L. 2017. "Contributions of Risk Preference, Time Orientation and Perceptions to Breast Cancer Screening Regularity." *Social Science & Medicine* 185: 147–157.

- Grady, Denise. 2015. "American Cancer Society, in a Shift, Recommends Fewer Mammograms." *The New York Times*, October 20. <http://www.nytimes.com/2015/10/21/health/breast-cancer-screening-guidelines.html>
- Knerr, Sarah, Karen J. Wernli, Kathleen Leppig, Kelly Ehrlich, Amanda L. Graham, David Farrell, Chalanda Evans, George Luta, Marc D. Schwartz, and Suzanne C. O'Neill. 2017. "A Web-Based Personalized Risk Communication and Decision-Making Tool for Women with Dense Breasts: Design and Methods of a Randomized Controlled Trial Within an Integrated Health Care System." *Contemporary Clinical Trials* 56: 25–33.
- Kranold, L., P. Hazarika, and M. Popović. 2017. "Investigation of Antenna Array Configurations for Dispersive Breast Models." In *2017 11th European Conference on Antennas and Propagation (EUCAP)*, 2737–2741. Paris.
- Lee, Eunice E., Mary-Lynn Brecht, Han Jong Park, Jongwon Lee, and Kyeung Mi Oh. 2017. "Web-Based Study for Improving Mammography Among Korean American Women." *Journal of Cancer Education* 32 (2): 257–263.
- Mainiero, M. B., A. Lourenco, M. C. Mahoney, M. S. Newell, L. Bailey, L. D. Barke, and B. G. Haffty. 2013. "ACR Appropriateness Criteria Breast Cancer Screening." *Journal of the American College of Radiology* 10 (1): 11–14. doi:10.1016/j.jacr.2012.09.036
- "Mammogram Guidelines @ The Breast Cancer Site." n.d. Accessed 19 October 2015. <http://thebreastcancersite.greatergood.com/clickToGive/bcs/mammogram-guidelines>
- McDonald, James Ted, Yunli Wang, and Zikuan Liu. 2017. "Participation and Retention in the Breast Cancer Screening Program in New Brunswick Canada." *Preventive Medicine Reports* 6: 214–220.
- Meadows, E. S., A. Whangbo, N. McQuarrie, N. Gilra, B. D. Mitchell, and J. L. Mershon. 2011. "Compliance with Mammography and Bone Mineral Density Screening in Women At least 50 Years Old." *Menopause (New York)* 18 (7): 794–801. doi:10.1097/gme.0b013e3182083f28
- Mokale, Santosh N., Afreen Begum, Nikhil S. Sakle, Vishakha R. Shelke, and Swati A. Bhavale. 2017. "Design, Synthesis and Anticancer Screening of 3-(3-(Substituted Phenyl)Acryloyl)-2H-Chromen-2-ones as Selective Anti-Breast Cancer Agent." *Biomedicine & Pharmacotherapy* 89: 966–972.
- Oeffinger, Kevin C., Elizabeth T. H. Fontham, Ruth Etzioni, Abbe Herzig, James S. Michaelson, Ya-Chen Tina Shih, Louise C. Walter, et al. 2015. "Breast Cancer Screening for Women at Average Risk: 2015 Guideline Update from the American Cancer Society." *Journal of the American Medical Association* 314 (15): 1599–1614. doi:10.1001/jama.2015.12783
- Paap, Ellen, André L. M. Verbeek, Anita A. M. Botterweck, Heidi J. van Doorne-Nagtegaal, Mechli Imhof-Tas, Harry J. de Koning, Suzie J. Otto, et al. 2014. "Breast Cancer Screening Halves the Risk of Breast Cancer Death: A Case-Referent Study." *The Breast*. Accessed 23 April 2014. <http://www.sciencedirect.com/science/article/pii/S0960977614000460>
- Pace, L. E., and N. L. Keating. 2014. "A Systematic Assessment of Benefits and Risks to Guide Breast Cancer Screening Decisions." *Journal of the American Medical Association* 311 (13): 1327–1335. doi:10.1001/jama.2014.1398.
- Qualtrics, Provo Utah. 2015. <http://www.qualtrics.com>
- Selby, J. V., A. C. Beal, and L. Frank. 2012. "The Patient-Centered Outcomes Research Institute (PCORI) National Priorities for Research and Initial Research Agenda." *Journal of the American Medical Association* 307 (15): 1583–84. doi:10.1001/jama.2012.500.
- Seven, M., G. Bağcivan, and A. Akyuz, and Ferdağ Bölükbaş. 2017. "Women with Family History of Breast Cancer: How Much are They Aware of Their Risk?" *Journal of Cancer Education*. <http://link.springer.com/10.1007/s13187-017-1226-3>
- Silva, Bruno M., Joel J. P. C. Rodrigues, Fábio Canelo, Ivo C. Lopes, and Liang Zhou. 2013. "A Data Encryption Solution for Mobile Health Apps in Cooperation Environments." *Journal of Medical Internet Research* 15 (4): e66. doi:10.2196/jmir.2498.

- Smith, K. P., and N. A. Christakis. 2008. "Social Networks and Health." *Annual Review of Sociology* 34 (1): 405–429. doi:10.1146/annurev.soc.34.040507.134601
- U.S. Preventive Services Task Force. 2009. "Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement." *Annals of Internal Medicine* 151 (10): 716–726. doi:10.7326/0003-4819-151-10-200911170-00008
- Vahabi, M., and D. Gastaldo. 2003. "Rational Choice(s)? Rethinking Decision-Making on Breast Cancer Risk and Screening Mammography." *Nursing Inquiry* 10 (4): 245–256. doi:10.1046/j.1440-1800.2003.00190.x
- Viens, Laura, Doug Perin, Virginia Senkomago, Antonio Neri, and Mona Saraiya. 2017. "Questions About Cervical and Breast Cancer Screening Knowledge, Practice, and Outcomes: A Review of Demographic and Health Surveys." *Journal of Women's Health* 26 (5): 403–412.
- Walter, E. Jane, Julia A. Knight, and Lothar Lilge. 2017. "A Multi-Wavelength, Laser-Based Optical Spectroscopy Device for Breast Density and Breast Cancer Risk Pre-Screening." *Journal of Biophotonics* 10 (4): 565–576.
- Watson-Johnson, L. C., A. DeGroff, C. B. Steele, M. Revels, J. L. Smith, E. Justen, and L. C. Richardson. 2011. "Mammography Adherence: A Qualitative Study." *Journal of Women's Health* 20 (12): 1887.